Mad in America
SCIENCE, PSYCHIATRY AND SOCIAL JUSTICE

People With Lived Experience Co-Produce Study on Combating Mental Health Stigma

People with lived experience (PWLE) of mental health conditions share their experiences of stigma and discrimination, highlighting the need for collaboration in anti-stigma efforts.

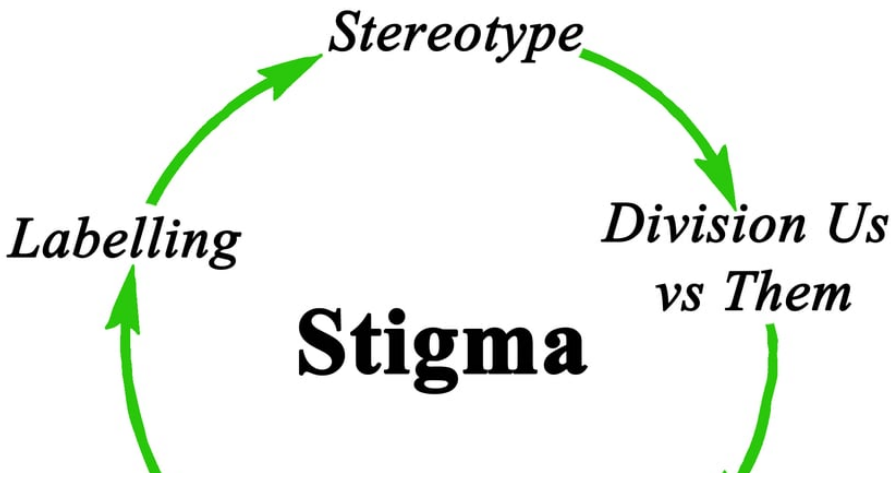
By **Richard Sears** - June 18, 2024

A new study out of King's College London, co-produced with people with lived experience (PWLE), reveals the pervasiveness of stigma and discrimination faced by people with mental health diagnoses.

The research, published in clinical medicine, part of The Lancet, identifies five key themes related to stigma and discrimination as reported by PWLE. These themes expose the impact of language, the role of media, societal reactions, knowledge of anti-stigma efforts, and personal experiences fighting stigma.

The authors, led by Petra C. Gronholm, emphasize the crucial role of PWLE in dismantling stigma. The study underscores the need for collaboration with PWLE, recognizing their expertise and ensuring their voices are heard in planning, delivering, and evaluating anti-stigma initiatives. This approach, centered on lived experience, is seen as critical to achieving lasting change. They write:

"The findings highlight that people with mental health conditions are aware of and experience stigma and discrimination across core domains of daily life. The importance of recognizing the key role PWLEs can play in efforts to reduce stigma and discrimination was highlighted, and how they can be appropriately supported to contribute and have their experiential expertise recognized."



Components of the cycle of stigma

The goal of the current research was to explore global perspectives from PWLEs around stigma and discrimination related to mental health conditions. The authors chose a co-production method in which PWLEs contributed as equals in conceptualizing the study, developing methods, interpreting results, and writing the research article.
The authors, who had lived experience of mental illness, developed open-ended survey questions about exposure to stigma and discrimination, language around mental health, the process of diagnosis, and involvement with anti-stigma organizations and work. The questions were then reviewed by an international panel of experts on stigma and methodology. Approved questions were presented in six languages: Arabic, Chinese, English, French, Russian, and Spanish. Between 12/1/2021 and 2/28/2022, the online survey was distributed to people through networks of mental health organizations that collaborated with PWLE.

Participant responses were fed through a word network analysis software called Infranodus. This software compiles data on word frequency and word clusters (groups of words that tend to appear together). The authors used the Infranodus results to establish themes in the survey responses. These themes were then refined through several waves of researcher discussions and workshops.

To be included in the study, participants needed to be over 16 years old, self-identified as a PWLE of a mental health condition, active in anti-stigma activities, and willing to talk about stigma and discrimination as a result of their diagnosis. In total, researchers collected responses from 198 participants.

The authors ultimately identified 5 main themes from the survey data:

1) The role of language and words

Participants were largely aware of negative terms used to describe people with mental health diagnoses (such as “psycho”). Although many participants pointed to specific inappropriate terms, the survey data also reflected an appreciation of context and cultural dependence to determine the appropriateness of language. Participants showed a preference for sensitive language in clinical settings, and many insisted that PWLE should be consulted on how they would like to be addressed. Language around diagnosis was seen as both positive and negative. Diagnostic language could help with treatment and support education and research around mental health, but this same language could also lead to stigma/discrimination while dismissing the social factors involved in mental health.

2) The role of media in perpetuating and reducing stigma

Media depictions of mental health issues were seen as having the potential for both positive and negative effects related to stigma and discrimination. Depictions of people with mental health diagnoses as dangerous, inappropriate language, and misinformation could all lead to increased stigma and discrimination. However, accurate and balanced depictions of mental health conditions could ease stigma by providing a platform for education and awareness.

3) Societal reactions to mental health conditions and strategies to cope with these

Participants largely viewed society as unsympathetic. Media, culture, and traditional beliefs were all implicated in exacerbating stigma and discrimination. Many participants expressed fear of disclosing their mental health conditions. These fears ranged from friends/family believing negative stereotypes to abandonment, isolation, and estrangement. Many participants also reported fear of disclosing their mental health condition to employers and healthcare professionals.

4) Knowledge about activities to reduce stigma and discrimination and their impact

Participants believed targeting education around mental health conditions to key groups, such as students, healthcare practitioners, and families of those with diagnoses, could help reduce the burden of stigma and discrimination. Participants also pointed to the importance of structural-level efforts. such as lobbying lawmakers for improved policy around mental health. Some reported that structural changes to laws and policies were the true measure of the reduction of stigma and discrimination.

5) Personal involvement in activities to reduce stigma and discrimination

Participants reported working in many different capacities and engaging with diverse target groups (schools, churches, hospitals, etc.) in their anti-stigma work. Some participants mentioned the challenges of anti-stigma work, such as negative reactions from others, reliving unpleasant experiences, belligerent event attendees, and difficulty in their personal lives as a result of publicly disclosing their mental health conditions. Participants also struggled with feeling as if their involvement in some anti-stigma activities was purely tokenistic. As a result, many participants emphasized that PWLE should be involved in leadership roles as well as planning, delivery, and evaluation of anti-stigma programs.

Participants reported several factors that could improve PWLEs' involvement in anti-stigma work, including a safe space to share narratives, organizational support, peer support, and compensation for their time and expertise. Candidness, meaningful conversation, improved self-confidence, improved self-agency, increased self-compassion, and reduced self-stigma were all reported as positive takeaways from participation in anti-stigma activities.

The authors acknowledge several limitations to the current research. The results are not representative of the larger population of PWLE. All participants had some history of work with anti-stigma programs. PWLEs that have not worked with anti-stigma programs may have very different perspectives. The current work did not consider the data based on certain subgroups, such as gender. The self-report nature of the survey means it was impossible to know if participants had mental health issues beyond their self-identifying as PWLE. Interviews, as opposed to online survey questions, would likely have produced better data.

The authors conclude:

"This study centered on the voices of people living with mental health conditions through sharing experiences and reflections on stigma and discrimination. Eradicating these negative experiences relies on collective action by multiple stakeholders (international agencies, governments, policymakers, healthcare sector, research institutions, mental health charities, media, communities, families, and PWLE) and aligning laws and policies with human rights treaties to accomplish effective accountability within policy and practice."

Research has found that stigma around mental illness is often driven by fear and misunderstanding. Essentialist thinking, that people and things have inherent and unchanging traits, may also increase stigma. While research has found that the biomedical model of mental health increases stigma, psychosocial approaches that acknowledge social factors of mental health can help reduce stigma. Anti-stigma campaigns that focus on brain-centered biomedical explanations have been unsuccessful. Pharmaceutical companies have also funded patient advocacy groups and used the charge of stigma to increase drug sales.

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Gronholm, P. (2024). Exploring perspectives of stigma and discrimination among people with lived experience of mental health conditions: a co-produced qualitative study. *eClinicalMedicine* 2024;70. (Link)

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Richard Sears teaches psychology at West Georgia Technical College and is studying to receive a PhD in consciousness and society from the University of West Georgia. He has previously worked in crisis stabilization units as an intake assessor and crisis line operator. His current research interests include the delineation between institutions and the individuals that make them up, dehumanization and its relationship to exaltation, and natural substitutes for potentially harmful psychopharmacological interventions.